

“Total Care for the Disabled Child”
Keynote Address
First International Conference on Pediatric Social Work
Chicago, Illinois
August 12, 1982

Here, I am talking about the arena where I spent forty years of my professional life caring for less than perfect children who, even properly cared for and sometimes operated on, do not end up pristine in form or function. I know this territory well and I take the listener from generalities through step-by-step suggestions for adding to our already large armamentarium. For example, preparing the pediatric and surgical staffs of hospitals for possible long-term relationships with some parents, the fact that the physician-patient relationship can no longer be casual nor short-term and communication has to be in words parents understand and not forget. Then there's the reminder that, in addition to the problem at hand, there are financial, emotional, and other issues. The physician must never transmit a sense of hopelessness or futility or in effect, go into mourning for a child who is still very much alive no matter how severe its physical or mental burden. Rejection of terms of hopelessness is not the same as offering false hopes to confuse and frighten parents, we need to be cautious, honest, and objective but we need to build on the family strength.

Complementary to all of the above, is to expand in strength of the facilitating skills of the social services staff.

We also have to control -- rather be controlled by -- the new technology of medicine and health care.

I lean heavily for examples on the respirator-dependent children with whom I had significant experience before becoming Surgeon General. This is the first time I mentioned in public, the plight of Katie Beckett, the need for Katie Beckett waivers, and my chairmanship of the Katie Beckett Waiver Board.

(Katie Beckett was a respirator-dependent child living in a hospital far from home with bills being paid for by Medicaid. We proved that Katie was better off at home, her cost there was \$ 800 a week rather than \$1500 a day in the hospital, and made Medicaid foot the bill at home. The chain of responsibility passed from Julie Beckett, Katie's mother, to congressman Tauke (Iowa) to Vice President Bush to President Reagan, to Secretary of Health & Human Services Schweiker, to the Surgeon General.)

Charities, vulnerability to
disguise
Control of new technology
of respirator dependent
children
High costs, (emotional &
monetary)

Disabled neonate-responsibility
of parents
Physician/patient relationship
Our stubborn innocence in dealing
with our own mortality
Special training of physicians &
nurses
Support of parents in the time of
need
The ambiguity of parent/child
relationship
The effort to give human life
a specific value
The expansion & strengthening
of facilitating skills
The improving infant mortality
rate
The reliability of love as a
primary motivation
The worth of social services
Tips on handling parent's
concerns

Children's Hospital of
Philadelphia
Secretary Richard Schweiker